

# A Thinking Ahead

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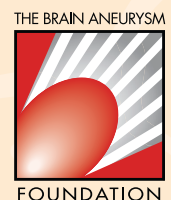
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## Amanda Horan Kennedy, Founder and CEO of Sassybax, Brain Aneurysm Survivor

Amanda Horan Kennedy's beauty queen head has received the crown of Miss Texas, was deemed picture-perfect in front of cameras for top brands like Lean Cuisine and Clairol, and was considered unusually sensible among Hollywood's young actors. However, Amanda's head was also a ticking time bomb with two brain aneurysms ready to rupture. Doctors diagnosed both by happenstance during an office visit in 2000 for unrelated dizzy spells.

Amanda beat the clock, and some might say death, by undergoing a CT scan before her aneurysms ruptured and taking a proactive stance to treatment. Her head was in good hands under the care of surgeon Dr. Neil Martin at the UCLA Hospital System, especially when an aneurysm ruptured right before his eyes in the operating room.

Amanda's recovery process brought her good fortune, too. Not only did she fully recuperate, but the process itself was the impetus for starting Sassybax, her multi-million dollar shapewear business launched in 2004.

During Amanda's recovery, the former model stopped her exercise routine and gained 15 unwanted pounds—a small concession after successful brain surgery, but a consequence she did not accept lightly, particularly on Valentine's Day evening when dressing for a date with her husband. To combat noticeable pounds that showed as bra bulge across her back, she concocted a makeshift control-top bra fashioned from a pair of cut-up pantyhose. The no-nonsense design that she slipped on over her head sparked an idea for an entire shapewear line that today sells at Neiman Marcus, Saks Fifth Avenue, and about 1,000 other stores across North America. Amanda credits her Sassybax brainstorm to her brain aneurysm experience and a touch of unrepentant vanity.

Amanda brings an interesting perspective to the \$4.1 billion bra industry, drawing from contrasting experiences as a Hollywood actress and trained psychotherapist. Her insights about a woman's figure and its effect on self-esteem largely drove her to create shapewear for women with real bodies like hers.

Her story, once told in *Entrepreneur* and *Millionaire Blueprint* magazines and on national television shows such as "Today" and "The Big Idea," is inspiring to women, entrepreneurs, and brain aneurysm survivors alike.

Once known as Barbra Horan, Amanda began modeling at the age of 14 for Hallmark Cards and earned the spotlight soon thereafter as a Calvin Klein model in the Midwest. Modeling continued through college, which led to the crown for Miss Texas and ultimately a career in Hollywood. A full-time actress at age 20, Amanda landed a starring role in the hit television series "BJ & The Bear." For more than 10 years, she appeared as the leading guest star in shows like "Cheers," "Dallas," "Remington Steele," "Hart to Hart" and "TJ Hooker," and acted in more than 200 national commercials for Clairol, Gallo Wine, Lean Cuisine and Michelob, among others. Film credits include "My Favorite Year" with Peter O'Toole and "Mortal Sins" with Christopher Reeve.

In spite of her acting success, she felt the toll Hollywood takes on a woman's self-esteem and returned to school at South Methodist University to study psychology. She earned a Masters Degree in Clinical Psychology and began her second career in her mid-30s, specializing in women's psychology.

After five years, Amanda's career took another turn, when doctors diagnosed her as having two brain aneurysms. She pulled down her shingle from her psychotherapy practice and she and her husband Bruce prepared for surgery and beyond.

Amanda has become actively involved with The Brain Aneurysm Foundation. She has pledged to establish the Amanda Kennedy Chair of Research for the organization and plans to help educate the public about the importance of early detection, particularly for women, who are more likely to form brain aneurysms at the ratio of 3:1. Her company, found online at [www.sassybax.com](http://www.sassybax.com), will also reach out to its thousands of women customers about the risks, diagnosis and treatment of brain aneurysms, tell them Amanda's story of survival, and direct them to the Foundation for

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## Crystal Clear

By: Christine Buckley LeBlanc

Fifteen years, in terms of one's life, brings you to young adulthood; a time in your life when you feel quite confident, yet really you are just starting to embark on your life's future. You are at the point where you are knowledgeable, but still gaining knowledge. You feel you are well equipped to make the necessary decisions aimed at shaping your life ahead. In reality, 15 years is nothing, it is only a beginning. In one's first 15 years, hopefully you have established a solid basis for which future growth and success can be developed. This is my hope for The Brain Aneurysm Foundation as it celebrates its 15th year of life in 2009.

Our first major undertaking of 2009 will be the production and distribution of an early detection video targeting the medical community to be more aware of the signs and symptoms of brain aneurysms and to consider brain aneurysms as a diagnosis, especially in cases where family history is a factor. We are thankful to Bill Demmer of Michigan for providing the funding needed to get this project off the ground. Bill lost his wife Shirley last year suddenly to a brain aneurysm rupture. Through his generosity and compassion, Bill hopes to prevent others from suffering a similar loss.

The Brain Aneurysm Foundation has grown fabulously in 15 years. This growth has come through dedication, hard work, a need, and the contributions of many. Although a celebration is in order after 15 years of service, we must all remember we have only poured the foundation for the future of brain aneurysm awareness, education, support, and research. We are at the point where we must make informed decisions from what we have learned in order to provide better support to

survivors and caregivers, provide more educational information to medical professionals to promote early detection of brain aneurysms, continue to raise funds to provide grants for research so more lives can be saved, and continually promote overall awareness in our communities each day.

The traditional anniversary gift for 15 years is crystal. Dictionary.com defines crystal as: "glass of fine quality and a high degree of brilliance". I believe after 15 years The Brain Aneurysm Foundation should be perceived as crystal - an organization of fine quality with a high degree of brilliance with an abundance of the quality and brilliance coming from all of you who support our mission on a daily basis.

For those who are available, I hope you can celebrate with us on March 29, 2009 from 11:00 – 3:00 at a jazz brunch to be held at the Fairmont Copley in Boston, Massachusetts to honor of two of the BAF's founders whose dedication today is as passionate as it was 15 years ago, Dr. Christopher Ogilvy and Deidre Buckley, N.P. Please visit our website for more details in the upcoming month.

Although I do not have a crystal ball, I guarantee The Brain Aneurysm Foundation will continue to prosper and strive to reduce the number of people affected by brain aneurysms in 2009. Thank you for your continued support and constant inspiration.

All the best for a healthy New Year!

Warm Wishes,

*Christine*



### Announcing New Monthly Pledge Processing Program at The Brain Aneurysm Foundation

For those wishing to pledge to make a monthly donation to The Brain Aneurysm Foundation by credit or debit card, we have established a new program in 2009. To make a pledge, simply fill out the donation information on the back of this newsletter with your monthly pledge amount and credit or debit card information, or for more information go to our website at [www.bafound.org](http://www.bafound.org) or contact [office@bafound.org](mailto:office@bafound.org)

## The First Brain Aneurysm Race for Awareness

### 8K in Memory of Timothy P. Susco in Reston, VA was a Great Success

The Brain Aneurysm Race for Awareness 8K in Memory of Timothy P. Susco was held on Saturday, October 4, 2008 under perfect weather conditions in Reston, Virginia. The race drew 670 runners from



as far away as Pennsylvania and Florida with proxy runners in Indiana and Arizona. The race went off without a hitch, thanks in part to the 130 volunteers who offered their time and support.

Tim Susco was a 1999 graduate of South Lakes High School and a graduate of Temple University. As a student at South Lakes, Tim was a member of the Track and Cross Country Teams. He was active in the Reston Youth Baseball League and he also earned the prestigious rank of Eagle Scout from Troop 1802. At the time of his tragic death, Tim was working in Hollywood, CA enjoying great success as a Key Assistant Location Manager on the television show "Heroes."

Tim put the maximum effort into everything that he did, and it was this effort and thirst for success that brought him to pursue a variety of interests throughout his life, playing baseball, running cross-country and track, serving as an altar boy, playing guitar, umpiring youth sports and obtaining the highest achievement in scouting, Eagle Scout.

It was at Temple University that he first discovered his love of film and television and realized that he wanted to pursue the field as a career. He worked on various projects in Philadelphia, including the movie "National

Treasure." In 2004, he moved to Los Angeles to begin his career in film.

It was in October of 2006 that he finally got his "big break" and landed a job on NBC's "Heroes," where he was an Assistant Location Manager. He was soon promoted to Key Assistant Location Manager. Last year, while scouting locations for Episode Six of Season

Two, Tim suffered a fatal brain aneurysm. That episode was dedicated in his memory.

The show "Heroes" depicts ordinary individuals who discover they have superhuman abilities. Tim couldn't leap tall buildings with a single bound, and he didn't have X-ray vision, or the ability to fly, or travel through time. But Tim was more of a hero than any of the characters on the show he worked on. His superhuman

abilities include his kindness, his patience, his ability to make others smile, his hardworking spirit and the ability to leave such a huge impact with so many people in so little time.

The majority of the Susco family was in attendance, either helping behind the scenes or to run in the race. In addition, various individuals participated in the race either as brain aneurysms survivors or in memory of their own lost loved ones. Team Barb and Team Leanne each brought over 25 people to remember the lives of their own loved ones that were also cut too short.

The funds raised were split

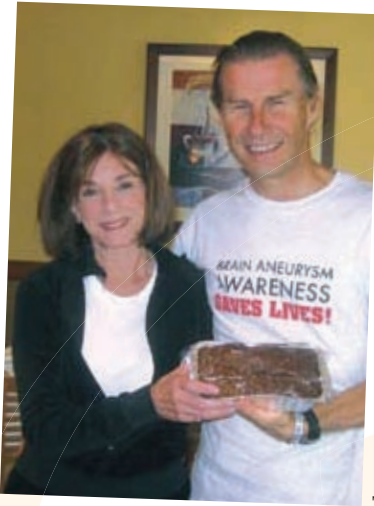


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## Man of Steel with a Heart of Gold Raises over \$14,000

By: Christine Buckley LeBlanc

November 23, 2008 in Tempe, Arizona was the site of the Ironman competition. As previously reported, Dr. Frank Eeckman competed in this Ironman to raise funds for The Brain Aneurysm Foundation and to promote brain aneurysm awareness in honor of Cindy Lynn Sherwin who suffered a brain aneurysm, which took her life at age 33. At the time of Cindy's rupture, she was training for her first Ironman.



I had the opportunity to meet with Frank, Cindy's mom Elaine and Cindy's best friend Jessica. This was a special meeting by people who had not known each other until a tragic loss brought them together. In the end, through tragedy came inspiration, excitement, friendships, and the determination to do more to prevent deaths due to brain aneurysms.

Never having witnessed an Ironman competition, the

experience was amazing. Watching 2000 plus people swim 2.4 miles, bike 112 miles, and then run 26.2 miles is extraordinary. I am happy to report Frank finished with his best time ever of 11 hours and 4 minutes. I think two things led to his better time: 1) Inspiration from Cindy 2) The special banana bread Cindy's mom made for Frank just like she used to make for Cindy before competitions!

Thank you Frank for your determination and kind spirit. Thank you Elaine and all of Cindy's family and



friends for sharing Cindy's memory and the story of her very full life and for supporting Frank's heroic Ironman competition. The generous corporate donation of \$5,000 made by Glaceau-Vitamin Water was also greatly appreciated. The proceeds from this event will be used to award a Research Grant in 2009 in the name of Cindy Lynn Sherwin.

## Sherry Bird Memorial Walk



The 1st Annual Sherry Bird Memorial Walk for Brain Aneurysm Awareness took place in St. Andrews, NB on October 5th.

Meagan Morrow, the walk organizer and Sherry's daughter,

reports: "This was the first walk to benefit The Brain Aneurysm Foundation in Canada and it couldn't have turned out better! The weather was great, nice and sunny with a little breeze. We had roughly 100 people come out to take part in that day, including several survivors and their family members, along with families who had lost a loved one to a brain aneurysm. The T-shirts and wristbands were big hits, we sold out of each. Altogether, with pledges and donations, we raised over \$3300 for The Brain Aneurysm Foundation!"

\*Save a tree, help The Brain Aneurysm Foundation go green. Email your email address to [office@bafound.org](mailto:office@bafound.org) to receive your Newsletter via email.

# Life Choices, A Brain Aneurysm Survivor's Story

By: Gail Bickford

I am a firm believer that we each have two choices in life. We can take our experiences and repeat them or we can learn and grow from them. Some seventeen years ago, I suffered the rupture of a basil aneurysm. I have no intention of repeating that event, but sharing what I have learned is something I long to do.

In 1991, neurosurgery was not an everyday event. It certainly was not something I or any family members were familiar with. Successful brain aneurysm surgeries were not common place. Outcomes were often bleak. When I was told what I would get back for skills would happen in the first year and a half, I was not a happy camper. Prior to my rupture, I was a child development specialist and taking graduate classes in family development. Planning and organizing for large groups was something I enjoyed. Suddenly, without warning, I could no longer do that. Making a peanut butter and jelly sandwich was a chore. I recall the day during my recovery when I realized I did not remember how to fold a towel!

I thought the 56 days in the hospital revealed my new skill level, or rather my skill losses. No way. The more I tried to assimilate into my old life, the more difficulties I discovered. Like many patients, I was caught in two places. Forever grateful for my life, but not able to make any sense of it, I went through the full range of emotions: anger, fear, unknowing and to this day persistent doubt. It is the doubting that trips me up each time. When you look at it closely, doubt and fear are like fraternal twins. They have some commonality yet differences. Both emotions cause us to question not only the situation, but ourselves as well. Often we stop in our tracks because one or both of these feelings catch us off guard. Insecurity takes hold. We are not able to function the old way for very sound medical reasons, nor are we able to function in new ways, because of the unknowing. When you know you are different than before it throws you for a loop. Let's face it, when all of a sudden you can read words but not know what they mean strung together, that would rattle anyone. Signing your name on a check and having to wait a few seconds so that your brain can remember how to make the next letter, doesn't exactly instill confidence! Yet that has been part of my life (in varying degrees) for the past seventeen years.

How, do I cope? Some days are better than others. Whatever you are dealing with, keeping it bottled up inside intensifies that fear, that unknowing. Talk about your fear, to yourself, perhaps to a friend, a stranger, a partner. Just say the words out loud! Saying things out loud seems to give me clarity. If not clarity, there is some comfort from honoring the way you feel. Writing is another way to say things out loud.

Sometimes I spend a fair amount of time rescheduling appointments and plans. I find I get particularly upset when I have to do so. For me it is the unknowing, that sudden change, that trips me up. In some cases (as it is today) it's because I messed up. I was confused, so many things I didn't remember.

Frequently since rupture, I have felt like the rug was pulled out from under me. I try to adjust to the change along with my new skill set. Sometimes it is like floating downstream and others it is like swimming against the tide in a storm!! Changes are in short, rescheduling! Sometimes we get to create the change and sometimes not. As humans we think we are in control of our bodies, our lives and others. Truthfully, God, Allah, the Goddess, the Supreme Being or the Power up above (which ever one fits your belief) is totally calling the shots.

Rescheduling involves two skills sets: actively listening and being participatory. It means you let others into your life, also in an active way. Try working together. Blend. So the next time you have to deal with change (especially if you forgot), try thinking of it as rescheduling. It is a new opportunity. A new chance to grow. It is truly amazing how working with yourself and not blaming or being self-critical can be uplifting. Everything seems to work out.

You can learn from your experiences which will help you determine which route is yours at that given moment. While you are traveling down that familiar road or a new one, go slow. Take time to see the new things. Experience them with joy or caution rather than loss. Then it will be one of those better days.

# Joe Biden, A Brain Aneurysm Survivor Success Story

By Ginny Comstock Tocci

No matter what your personal political preferences are, it will be an amazing day on Inauguration Day on January 20th 2009, when a two time brain aneurysm survivor gets sworn in as Vice President. Joe Biden is a very lucky man. First elected into the U.S.



Senate from the state of Delaware in 1972, Biden recovered from near-fatal aneurysms in 1988 to continue to serve in the Senate and is now Vice-President Elect of the United States.

In 1988, Biden suffered with headaches, nausea, and increasingly severe neck pain for weeks, finally collapsing in a New York hotel room. He wrote in his autobiography "Promises to Keep" that it felt like "lightning flashing inside my head, a powerful electric surge—and then a rip of pain like I'd never felt before." He was rushed to the Walter Reed Army Medical Center where doctors discovered a ruptured aneurysm. His condition was considered grave and a priest was called in to administer last rites. Fortunately, neurosurgeons were

able to save Biden's life by performing clipping surgery to correct an intracranial berry aneurysm that had begun leaking. Biden wrote: "As I heard it, my chances of surviving the surgery were certainly better than fifty-fifty, but the chances of waking up with serious deficits to my mental faculties were more significant."

Through screening, a second aneurysm was discovered a few months later and surgically clipped before it burst. Recovery kept Biden out of the Senate for seven months. Amazingly, Biden overcame two clipping surgeries requiring craniotomies, to go on to become a leader in the U.S. Senate for the next 20 years until he takes the oath of office as Vice President of the United States on January 20, 2009. He is a very lucky man to have had access to great medical care, to overcome the odds of surviving two brain surgeries, and to have made such a complete recovery.

Joe Biden's story illustrates for those of you who may be facing surgery for a brain aneurysm or are in recovery, it is important to remain hopeful about your recovery, continue challenging yourself every day, and keep your dreams alive!

## Thank You to Senator Kerry for Increased Brain Aneurysm Awareness

(Senate—September 30, 2008 [Page: S10166])

The Brain Aneurysm Foundation would like to thank Senator Kerry of Massachusetts for presenting the following statement on the Senate floor on September 30, 2008 in support of brain aneurysm awareness, education, and research.

--- Mr. KERRY. Mr. President, I would like to take a moment to discuss an important medical condition that, in my opinion, is in need of increased attention. Brain aneurysm is defined by the National Institute of Neurological Disorders and Stroke, NINDS, as, "the dilation, bulging, or ballooning-out of part of the wall of an artery in the brain." Nationwide, there are 27,000 patients who each year have a ruptured aneurysm. But an estimated 6 million Americans currently live with an unruptured brain aneurysm. In Massachusetts alone, more than 1,000 cases of brain aneurysm are treated

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annually. With few symptoms, brain aneurysm is a condition that can strike without warning and have a devastating impact on individual lives and families in our country and abroad.

I applaud the efforts of the medical profession, research institutes such as the National Institutes of Health, NIH, and nonprofit organizations and groups such as the Brain Aneurysm Foundation who work tirelessly to combat brain aneurysm. Such work is critical to increasing the medical research and education that will lead to breakthroughs in the diagnosis and treatment of this devastating condition.

During the month of September, conferences and meetings are taking place across the country to raise brain aneurysm awareness. I want to recognize Massachusetts as one of several States which have

# Aneurysm Survivor Starts BAF Support Group and 1st Annual 5K/3K Fun Run and Walk in San Antonio

By: Mayra Kent

The tragedy of a ruptured aneurysm is impossible to put into words. Indeed, even as a survivor of an aneurysm that was found on routine screening for an unrelated problem and treated, I cannot begin to appreciate the fear and pain that ruptured survivors must endure. But in my case, the anxiety of sitting on a time bomb was something that my family and I had no way to prepare for.

It turned out to define all of my future priorities and the meaning for my life. I thought the most difficult decisions in my life would be to decide how, when, and if to get this thing in my head treated. But that was only the beginning. After four long months, I finally agreed with my surgeon's recommendation for coiling. Unfortunately, his recommendation included having a stent placed in the parent vessel six weeks before the coiling—a procedure that had never been done at the hospital where I was to be treated. The stent placement went as planned, but the side effects were tremendous and their magnitude was unanticipated. Not only was the headache pain severe, but my speech difficulty was frustrating and I had the additional anxiety and fear that when my actual coiling was done that the side effects could be just as bad if not worse.

Everything turned out fine. Both the stent placement and the coiling went just as planned, medically. Now I have my life to cherish and a new perspective on this terrible medical problem that silently and certainly affects more people than we know. After all, mine was found by pure luck. But from my point of view, the side effects from the procedures were terrible. To make matters worse I felt alone. The medical staff was all very professional and supportive but nobody could really identify with what I was going through. I had nobody

to call and talk to who could say "I understand." So that became my mission. I decided that my survival



was God's way of telling me to help those who also had to deal with this illness.

In November 2007, I did a search on the Internet. I found The Brain Aneurysm Foundation (BAF) and found that in just a few cities in the United States, local chapters had been established

to support those people affected. By this time I had been speaking with my neurosurgeon, Dr. Christopher Koebbe, and with his support and encouragement, I began at looking at ways of starting a local support group. In June 2008, I founded the San Antonio Support Group with just two members. It became rapidly apparent that we shared a common bond that no others could appreciate. We realized the importance of local support from people that had gone through similar experiences and problems. Furthermore, it became even more exciting when my surgeon, Dr. Koebbe, expressed interest in participating with our group as our medical advisor to assist with our countless medical questions and frustrations.

Then came the idea of putting together a "fun run" to increase awareness. I heard through the BAF of the successful walk that Cindy Phillips had organized for her good friend Sheryl Baker. Cindy and Sheryl's huge success in their run inspired me to put together our 1st Annual 5K/3K Fun Run and Walk. Their ideas and support were instrumental in making the San Antonio run a success. We began with the goal of having the run in October 2008, but that meant getting everything done in just a few short months. Our San Antonio Support Group team worked together to make it happen. The run was important to us to get even more support from

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## The BAF Attends North Shore University Hospital Symposium

On November 7th, The Brain Aneurysm Foundation staff was invited to attend The Neurovascular Symposium in Long Island by The Brain Aneurysm Support Group Circle of Friends at the North Shore University Hospital. The Circle of Friends Support Group was started just over a year ago and we were delighted to attend the Symposium and meet some of the members of the Support Group. We found that the North Shore University Hospital has a unique full cycle approach to caring for all their patients' needs from the preliminary evaluation of a brain aneurysm, through surgical or neuro-interventional radiological treatment, through recovery, rehabilitation and through providing emotional support after leaving the hospital.

The North Shore University Hospital has a transdisciplinary approach to caring for their patients. The Neuro-Interventional Radiology, Neurosurgery, Intensive Care Unit, Neuroscience Floor, Physical Therapy, Occupational Therapy, PA's, NP's, staff nurses, care coordination, and social work teams work cohesively to offer high-quality care. Their focus is to maximize recovery for their brain aneurysm patients and those affected with subarachnoid hemorrhage. Their goal as a team is to maximize the recovery process for patients and their families. Once discharged to rehab or home, patients may feel lost. They are left to deal with the devastating and traumatic effects of an aneurysm/SAH. Many times, it doesn't end there. There is a continuing effort to care for the patient once they leave the hospital setting. With this, patients are invited to attend North Shore's monthly brain aneurysm support group. Information about the support group and emotional support are provided. Contact numbers are given so that patients and family members can reach out to a team member with any questions or concerns they may have.

The Circle of Friends Support Group offers survivors and their families the opportunity to share life experiences, work through challenges and find new ways to adapt to changes in their life. They have the opportunity to meet other people who are going through the same difficult times as they are. They are no longer alone once they have entered The Circle. They

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share their experiences and some show support to those that are in need. They are part of the family from the moment they join the support group.

The Brain Aneurysm Support Group is a huge success with 30 attendees each month. Patients continue to come together in a non-stressful, relaxed environment where they feel comfortable expressing feelings and asking questions. Nothing speaks louder than personal experience. Here are some words from support group members:

Even though it was the first time I attended the group there was such a kindred ship among all of us. Even though we didn't know one another personally, in a sense we did, because we were all connected and had shared a very distinct experience. That first meeting was extraordinary because for the first time since my aneurysm, I was able to be around people who were just like me, people that could understand exactly what I meant, not because of the words I expressed, but because they had been through it too. It was the first time in a very long time I experienced a sincere feeling of belonging. The staff was wonderful and supportive and loving. I appreciated being so embraced and welcomed by everyone. —JA survivor

The best surgeons in the world will fail without the presence of good nursing. After my wife's aneurysm, I discovered that NSHS has the finest nursing that I have ever seen in health care. I owe her survival to the nurses as well as the surgeons. The Circle of Friends is just the natural extension of the compassionate and caring culture that the nurses of NSHS have created. The healing of the spirit is just as important as that of the body. —RK, Caregiver

The Circle of Friends Brain Aneurysm Support Group meets monthly at North Shore University Hospital in Manhasset, NY in the 9 tower conference room from 5:30 – 8pm. All are welcome to attend. The Circle of Friends Support Group grows larger and stronger each month. For more information contact Nicole Salant, R.N. at 516-562-3815 or Jennifer Laffey, F.N.P. at 516-562-3021.

# Large Study Identifies New Genetic Risk Factors for Brain Aneurysm

HHMI Howard Hughes Medical Institute Research News November 9, 2008

**B**y sifting through the genomes of more than 10,000 people, researchers have discovered three genetic factors that could help doctors identify people who are at the greatest risk for developing a brain aneurysm.

Howard Hughes Medical Institute investigator Richard P. Lifton and Murat Günel, geneticists at Yale University School of Medicine, led an international team of researchers that identified the risk factors. Any individual may have up to two copies of each of these genetic sequences, which the scientists call risk alleles. Those who carry five or six risk alleles are three times more likely to develop a brain aneurysm than those with one or no risk alleles.

The study is the first genome-wide search for common genetic variations that impact the formation of brain aneurysms. The team's findings are reported on November 9, 2008, in an advance online publication in the journal *Nature Genetics*. Researchers in Finland, the Netherlands, and Japan provided patient data for the study, and genetic analyses were conducted at Yale.

Most people with an aneurysm, or bulging blood vessel, in their brain never know it is there until it ruptures, causing a stroke that usually leads to catastrophic neurological damage or death. But if doctors can find an aneurysm before it causes a stroke, it can often be surgically removed to eliminate the threat. Assessing the new genetic information in combination with the other factors known to influence risk of aneurysm—age, gender, smoking, and high blood pressure—could allow doctors to identify which people are at highest risk and would benefit from screening, the researchers say. Screening could be performed by non-invasive imaging of blood vessels in the brain. Further, exploring the biological roles of the genes affected by the three risk alleles could provide clues into what causes aneurysms to form, a process about which Lifton says, we know almost nothing.

About two percent of people alive today are thought to have brain aneurysms, according to the American Heart Association. Many of these never cause any problems. In the subset of aneurysms that eventually rupture, the resulting stroke is usually the first symptom a patient experiences. Some aneurysms, however, can put

pressure on surrounding tissue, causing what patients typically describe as 'the worst headache of their life,' Lifton says. Those patients are the lucky ones, he says, since angiograms of the brain can identify clinically important aneurysms that can be surgically corrected before they cause lasting damage.

We do a pretty good job treating these aneurysms before they rupture, says Günel, who is a neurosurgeon. But when a patient suffers a hemorrhage and then comes to the hospital, sometimes despite the best medical care, there's not much you can do. So, he says, there is a big need for tools to help clinicians find treatable aneurysms in more patients.

Equally important, Lifton notes, is figuring out what causes these bulges in blood vessels to form in the first place. We really haven't known anything about the underlying biology of aneurysm, he says. If we can figure that out, it may give us an opportunity to intervene therapeutically—that is, with a drug, instead of surgery.

According to Günel, there have been only limited attempts to sift through the genetic factors that contribute to brain aneurysms so far, and these studies have searched for genes that have strong effects, but occur only rarely within a population. Only recently has the technology become available to do the large, genome-wide association studies needed to search for risk factors that are more common, but whose effects may be too subtle to pick up in small study population.

To mine for these common genetic factors, Lifton, Günel, and their colleagues compared the genomes of more than 10,000 individuals—2,100 of whom had brain aneurysms (both ruptured and unruptured) and 8,000 who did not. Specifically, they examined more than 300,000 single nucleotide polymorphisms (SNPs). SNPs are found throughout the human genome and represent instances where a single letter of the DNA sequence frequently varies between individuals. The team was looking for SNPs for which one allele was significantly more common among individuals with aneurysms than among those without aneurysms.

To begin the study, collaborators in Europe identified  
(continued on page 15)

## Save the Date—2009

March 29

### Sunday Jazz Brunch in Boston

Come join The Brain Aneurysm Foundation at The Fairmont Copley Plaza in Boston from 11 A.M. – 3 P.M. as we celebrate The Brain Aneurysm Foundation's 15th Anniversary and honor founders Dr. Christopher Ogilvy and Deidre Buckley, NP

May 24

8th Annual Arterial Challenge 5K Road Race and 1.5 Mile Walk, Marshfield, MA

July 20

Fourth Annual BAF Golf Tournament at Indian Pond Country Club, Kingston, MA

September 17

### Third Annual Research Grant

Awards Symposium, Chicago, IL

Featured speakers will be Robert D. Brown, Jr., M.D., Mayo Clinic and Fernando Vinuela, M.D., Ronald Reagan UCLA Medical Center

## Now Available in Spanish

We are happy to announce that the popular Brain Aneurysm Basics brochure, with Mario Batali on the cover, is now available in Spanish. To order "Información sustanciosa: Datos básicos sobre los aneurismas cerebrales que puede salvarle la vida," please contact [office@bafound.org](mailto:office@bafound.org).

(continued from page 3 "Amanda Horan Kennedy")

additional information and help.

The Brain Aneurysm Foundation is very pleased Amanda has come forward to share her wonderful

story of success and inspiration. The Foundation looks forward to working with Amanda and Sassybax in the New Year to help promote awareness and education of this often life-altering condition.

(continued from page 5 "Timothy Susco")

between The Brain Aneurysm Foundation (<http://www.bafound.org>) and the Washington Regional Transplant Community (<http://www.beadonor.org>).

The Brain Aneurysm Foundation is establishing a Research Chair in Tim's memory to be announced at the 2009 Third Annual Research Grant Awards Symposium in Chicago which will enable researchers to perform critical research that can directly benefit those affected and help to reduce the incidence of ruptured aneurysms so that other families will not have to go through the same tragic loss the Suscos have suffered.

The Washington Regional Transplant Community is a non-profit organization established in 1986 that serves as the organ procurement organization for Washington D.C., Northern Virginia, and suburban Maryland, as well as providing support and education to organ recipients, potential donors, donor families, and the general public. While Tim's life was cut too short, his lasting legacy is his ability to help save the lives of others through organ donation. Tim was able to donate his kidneys, his liver, his heart, and his lungs. Organ donation can save up to 50 lives and touch the lives of many more.

## The 2nd Annual Research Grant Symposium

The Brain Aneurysm Foundation had a wonderful evening during Brain Aneurysm Awareness Month in Philadelphia at The Union League on September 17, 2008. The Foundation awarded \$40,000 in brain



aneurysm research funding. The evening was hosted by Medical Advisory Board member and Chair of Research Committee, Robert Rosenwasser, M.D., FACS, Professor of Radiology and Neurosurgery at Thomas Jefferson University Hospital. There were over 100 people in attendance including medical professionals, medical corporations, and people affected by brain aneurysms.

The attendees were fortunate to hear three wonderful presentations on current brain aneurysm research from top neurosurgeons from around the world. The speakers included: Stephen B. Lewis, M.D., Cerebrovascular and Skull Base Surgery, Department of Neurosurgery at the University of Florida—Gainesville; R. Loch MacDonald, Head, Division of Neurosurgery at St. Michael's Hospital at the University of Toronto and Andrew Molyneux, M.D., Neuroradiologist, Radcliffe Infirmary NHS Trust in Oxford, England.

The highlight of the evening was the presentation of the awards. The recipients were as follows:

The recipient of the Shirley Dudek Demmer Chair of Research in the amount of \$20,000 was Satoshi Tateshima, M.D. of The Regents of UCLA. Dr. Tateshima's research project is entitled "Histopathology and Hemodynamics During the Growth of Brain Aneurysms." This research will study how and why the

wall of the aneurysm weakens over time in the hopes of helping doctors make appropriate clinical decisions in the management of patients with a small aneurysm that shows some change in shape and size over time. Investigators will look at brain aneurysm cells, study the interaction of some proteins in those cells, the shape and size of aneurysm as they grow, and how blood flow inside and around the aneurysm can affect aneurysm growth and/or rupture.

The recipient of the Cindy Lynn Sherwin Chair of Research in the amount of \$10,000 was Bernard Bendok, M.D. of Northwestern University. Dr. Bendok's research titled, "An Investigation of Inflammation Related Genes and CXCR4 in Human Cerebral Aneurysms" aims to better define the role of inflammation in brain aneurysms to open avenues for prevention, early detection, screening and therapy. His study will include the use of gene chips to identify inflammation related genes and what different characteristics these genes have when found in an aneurysm versus a different artery in the brain.

The third grant recipient in the amount of \$10,000 was Douglas Cook, M.D. from Toronto Western University Research Institute. Dr. Cook's project, "Endothelial and Vascular Smooth Muscle Differential Gene



Expression in Macro and Microcirculatory Vasospasm Following Subarachnoid Hemorrhage" will focus on identifying specific genes which are related to a condition called vasospasm, which is the narrowing of a blood vessel after it has been in contact with blood after aneurysm rupture.

(continued on page 15)

(continued from page 8 "Increased Awareness")

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declared the month of September as "Brain Aneurysm Awareness Month." Such declarations show that States across the country understand the importance of raising awareness of this condition and are taking the time to

highlight the need for additional education. I support these efforts and look forward to Congress working in a similar fashion in the near future.

(continued from page 9 "San Antonio Support Group")

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local San Antonio survivors and spread awareness.

Organizing and preparing for the run was a tremendous amount of work. Our support group is focused in a suburb of San Antonio and that turned out to be a blessing. The city leaders of Schertz, Texas soon became very excited and supportive. The more people I met, the more enthusiastic I became. In fact, as I met local business leaders in an effort to advertise the event, I met more people who had also been affected by a brain aneurysm themselves or had a family member who had been affected. Donations of time, supplies, and services were made by virtually everybody we contacted.

being told each time that this was something that they had been needing to do for years. We had a dedication tree that will be planted in the park in Schertz, TX where the Run/Walk took place that was dedicated to the survivors that attended and also to those we have tragically lost to this silent monster. We also had a release of over 100 butterflies that were shipped in from Florida from the son of man that lost his life to a brain aneurysm. We did this as a sign of hope and peace. I look forward to putting together next year's run. I've met such wonderful people that have touched my life in ways that words cannot describe. The best that I can do is look forward to increasing awareness here in San Antonio for just one more year (I move in June of 2009) and know that where ever the Air Force takes us...there will be a new support group of the BAF started!

Registration for the event got off to a slow start. Although we received website support and priceless advertisement, few people had registered just weeks before the run. Our support group was still relatively small and there was seemingly too much work and too little time. The week before the run, we were crossing our fingers that promises would come through and the weather would cooperate.

Dr. Koebbe commented: "After all that I have seen as a neurosurgeon, very few things happen that both surprise and overwhelm me until participating in San Antonio's First Brain Aneurysm Awareness Walk/Run. I was in awe of the efforts put forth and successes achieved by the local BAF support group as well as the turnout of walkers/runners coming from hundreds of miles away. The event not only raised a significant amount of money for the BAF but provided hope and comfort for so many whose lives have been changed by a brain aneurysm."

Not only was our participation more than double what we predicted, our sponsors came through with more support than we could have imagined. Over 200 people came to show support for our BAF San Antonio Support Group and over \$10,000 was raised by participants and sponsor donations. We had people travel from as far away as Missouri, Corpus Christi, and Laredo. We had perfect weather and it was just incredible to be able to meet and share survivor stories with people. I was also honored to sit and talk with several families that had traveled from out of state to walk in honor of their mother whom had died from an aneurysm,

I am humbled and in awe to have been surrounded by such grateful people. All I could think of when I was being thanked for putting this together was...in the end...they had helped me heal...like Cindy Phillips and Sheryl Baker put it so well, 'I was not alone anymore!'

(continued from page 10 "University Symposium")

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The Brain Aneurysm Foundation currently sponsors 30 support groups nationwide and in Canada, with new groups recently established in Fort Myers and the Twin Cities. However, many patient needs are still left unmet in many locations where The Brain Aneurysm

Foundation has not yet been able to establish a support group. To learn more about establishing a support group in your area or at your facility, please contact [office@bafound.org](mailto:office@bafound.org).

(continued from page 13 "2nd Annual")

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The Brain Aneurysm Foundation is pleased with the growth in its research grant program from the quality and quantity of its applicants, to the renowned neurosurgeons who attend to share their research

findings. The Foundation looks forward to awarding over \$100,000 in research grants on September 17, 2009 in Chicago!

(continued from page 15 "New Genetic Risk Factors")

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patients with aneurysms and control subjects—1,805 in Finland and 7,205 in the Netherlands. The researchers then determined these individuals' DNA sequence at 300,000 sites of common variation within the genome. These sites are distributed across all of the chromosomes. By comparing the frequency of each variant in individuals with and without aneurysm (cases and controls), the team identified four sites in the genome where a particular sequence variant was significantly more frequent in cases than controls. To confirm these results, the team then studied these 4 chromosome segments in an independent group of 1,171 Japanese subjects. Three of the sites showed the same association to aneurysm found in the Finish and Dutch populations, providing strong evidence that the results were not obtained by chance. Lifton points out that, since the risk alleles are present in both the Japanese and the European populations, whose overall genetic backgrounds vary more than groups within Europe, These findings are likely to be relevant for a very large fraction of the world's population.

Each of these three variants has a fairly modest impact on risk, Günel says—each copy increasing risk by 24 to 36 percent. But when you compare those with the fewest risk alleles to the group with the most risk alleles, the risk of an aneurysm goes up about threefold. In addition, Günel indicates that there are likely many other alleles that increase risk to a smaller degree—but a larger study will be required to find them.

This information starts to put us on a path toward being able to identify patients who should be screened for brain aneurysms, Lifton says, noting that when the newly identified genetic risk factors are combined with other known risk factors, they will account for a larger difference in risk between individuals. Similarly, Günel adds, patients with the greatest risk can be counseled on lifestyle changes, such as reducing blood pressure and quitting smoking.

The team's findings also have hinted at how some brain aneurysms might develop. One of the risk alleles identified in the study lies near a gene called *SOX17*. Endothelial cells, such as those that line the interior of blood vessels and come in direct contact with the blood, need *SOX17* for their formation. Another of the risk alleles had been previously implicated in other arterial diseases, including heart attack and abdominal aneurysms. That allele lies near a gene that is turned on during aging—which might be the case for genes needed to repair the damage that blood vessels accumulate throughout life, Günel says. We know that most aneurysms occur at branch points in the vessels, possibly due to increased stress on the vessel wall, Lifton says. So it may be that ineffective repair of this damage is responsible for the formation of an aneurysm. Further exploration using animal models will help test this model and determine whether researchers might be able to target the endothelial repair process for potential therapies, he says.

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# DONATE

I/we want to help The Brain Aneurysm Foundation continue to provide critical awareness, education, support and research funding to reduce the incidence of brain aneurysms. I/we want to help support the continued publication of The Brain Aneurysm Foundation newsletter **Thinking Ahead**.

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